



ADVANCING RARE DISEASE RESEARCH:

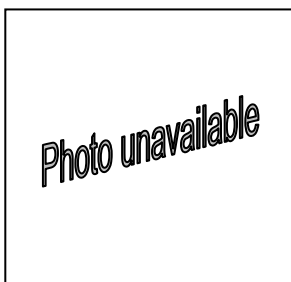
The Intersection of Patient Registries, Biospecimen Repositories, and Clinical Data

January 11–12, 2010 • Doubletree Hotel & Executive Meeting Center • Bethesda, MD

SPEAKER BIOGRAPHIES



Sukirti Bagal, M.D., is the director of medical affairs at the National Organization for Rare Disorders (NORD). She manages the rare disease database within the Information Services Department and currently is involved in developing new and strategic initiatives to broaden NORD's work. Prior to joining NORD, she was the director of emergency response at AmeriCares, the world's largest international disaster relief organization, and later served as the director of strategic planning at AmeriCares for the launch of AmeriCares India. Dr. Bagal is a well-known international public health physician and has been invited to speak at the United Nations on various public health topics.



Ronald J. Bartek is cofounder and president of the Friedreich's Ataxia Research Alliance (FARA), a nonprofit organization supporting medical research, and a 4-year member of the National Institutes of Health (NIH) National Advisory Neurological Disorders and Stroke Council. He is a former partner and president of a business and technology development, consulting, and government affairs firm and has 20 years of federal executive branch and legislative branch service in defense, foreign policy, and intelligence. Following graduation from the United States Military Academy at West Point, he spent 4 years as an Army officer, serving as a company commander in Korea and an infantry and military intelligence officer in Vietnam. He received his master's degree in Russian area studies from Georgetown University.



Christophe Bérout, Pharm.D., Ph.D., is an assistant professor at Montpellier I University, a lecturer at the Paris VI University, and an assistant professor in the Molecular Genetics Laboratory of the Montpellier University Hospital. He also is the head of the Biological Resource Centre's nucleic acids section, the head of the bioinformatics team, and the head of the team involved in the development of a noninvasive prenatal diagnosis technique using circulating fetal cells from maternal blood and congenital muscular dystrophies. He received his pharmacist degree, Pharm.D., and Ph.D. in human genetics from the Paris VI University.





Kyle Brown, B.S., is the founder of Innolyst, a technology company providing solutions to not-for-profit disease research foundations and large pharmaceutical companies to accelerate collaborative translational research programs. Innolyst has worked with a wide spectrum of life sciences organizations including Eli Lilly, Pfizer, Merck, Incyte Genomics, Theravance, Novartis, and more than 40 disease research foundations. Prior to Innolyst, Mr. Brown was founder and CEO of Ignite Knowledge Management, founder of Project Solutions, and principal IT manager at Sun Microsystems. His research areas of interest are informatics, Web-based technologies, and collaboration methods. Mr. Brown received his B.S. in business from Indiana University.



Ronald A. Christensen, M.D., is a senior executive at Registrat-Mapi, a global late phase contract research organization (CRO). He is involved in the strategic design, implementation, and management of hundreds of late phase studies for post-marketing safety surveillance, clinical effectiveness, outcomes research, and risk management. He has broad-based experience in academia, clinical research, and the biopharmaceutical industry. Prior to joining Registrat-Mapi, Dr. Christensen was a director in the marketing and medical affairs departments at Genentech, Inc., where he was responsible for the design and implementation of the National Registry of Myocardial Infarction (NRM) and the Epidemiological Study of Cystic Fibrosis (ESCF). He also managed the National Cooperative Growth Study (NCGS), a registry of growth hormone treatment.



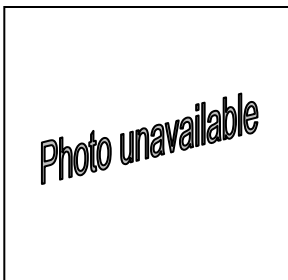
James J. Cimino, M.D., is chief of the Laboratory for Informatics Development at the National Institutes of Health (NIH) Clinical Center and a senior scientist at the National Library of Medicine (NLM). He is charged with the development of an institute-wide Biomedical Translational Research Information System (BTRIS) and conducts clinical informatics research. He received an Sc.B. in computers in the biomedical sciences from Brown University and an M.D. from New York Medical College. He interned and completed residency training in medicine at Saint Vincent's Hospital in New York and completed a research fellowship in medical informatics sponsored by the NLM at Massachusetts General Hospital and Harvard School of Public Health. Dr. Cimino has been an active member of the NLM Board of Scientific Counselors, cochair of the HL-7 Vocabulary Technical Committee, and a member of the board of the American Medical Informatics Association. He is a fellow of the American College of Medical Informatics, the American College of Physicians, the American Clinical and Climatologic Association, and the New York Academy of Medicine.



Carolyn Compton, M.D., Ph.D., is the director of the Office of Biorepositories and Biospecimen Research (OBRR) and the acting director of the Office of Technology and Industrial Relations (OTIR) within the Center for Strategic Scientific Initiatives at the National Cancer Institute Office of the Director. She also is an adjunct professor of pathology at the Johns Hopkins School of Medicine. Her current research involves translational studies in colon cancer and human biospecimen science. She received her M.D. and Ph.D. from Harvard Medical School and the Harvard Graduate School of Arts and Sciences. She trained in both anatomic pathology and clinical pathology at Harvard's Brigham and Women's Hospital.



Sue Dubman, B.A., M.A., currently is spearheading implementation of clinical data standards for Genzyme Corporation. This includes accountability to ensure effective rollout of data standards on an end-to-end basis throughout the clinical data lifecycle as well as ensuring that future system and data architecture support a high degree of data interchange and reusability. In her current role, Sue and her team have responsibility for the architecture of Genzyme's RegistryNXT platform for lysosomal storage diseases (LSDs). She has more than 20 years of experience in life sciences and health care. Sue completed work toward her Ph.D. in population sciences at Brown University and received her M.A. and B.A. from the University of Missouri, where she also taught statistics and computer science courses.



Lynn Etheredge is an independent consultant on health care and social policy issues and works with the Rapid Learning Project at George Washington University. His career started at the White House Office of Management and Budget (OMB). During the Nixon and Ford administrations, he was OMB's principal analyst for Medicare and Medicaid and led its staff work on national health insurance proposals. Lynn headed OMB's professional health staff in the Carter and Reagan administrations. Later, he was a coauthor of the Jackson Hole Group's proposals for health care reform and a founding member of the National Academy of Social Insurance. He is author of more than 85 publications and is a graduate of Swarthmore College.



Amy Farber, Ph.D., is the founder and CEO of the LAM Treatment Alliance (LTA), a 501(c)(3) nonprofit organization. After being diagnosed with lymphangioleiomyomatosis (LAM) in April 2005, Dr. Farber founded the LTA with the goal of fast-tracking bench-to-bedside research to find a treatment for LAM in time for women now living with the disease. She is trained as a social scientist focused on the study of law, medicine, and society and received her B.A. from the University of California Berkeley and Ph.D. from Harvard University. She completed a fellowship in medical ethics at Harvard Medical School and is a member of the Harvard Medical School faculty and the institutional review boards of Brigham and Women's Hospital and Massachusetts General Hospital in Boston.



Jennifer Farmer, M.S., C.G.C., is the executive director of the Friedreich's Ataxia Research Alliance (FARA), where she helps to carry out the strategic mission of the organization through administering FARA's research grant, scientific conference, patient registry, and education and awareness programs. Prior to joining FARA she worked at the University of Pennsylvania and Children's Hospital of Philadelphia. As a genetic counselor at the University of Pennsylvania Jennifer helped to establish the Division of Medical Genetics, focusing on adult genetics, and later became the division administrator. She developed a special interest in neurogenetic conditions and then went on to establish and coordinate clinical and research programs for individuals and families diagnosed with FA and related neurodegenerative diseases. She is one of the founders and the coordinator for the Collaborative Clinical Research Network in FA. Jennifer has a master's degree in genetic counseling.



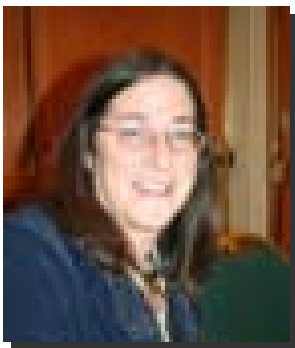
W. Andrew Faucett, M.S., C.G.C., is an assistant professor in the Department of Human Genetics and the director of the Genomics and Public Health Program of Emory University School of Medicine. He is the program coordinator for the National Institutes of Health (NIH) Office of Rare Diseases Research (ORDR) Collaboration, Education and Test Translation (CETT) program for rare genetic diseases. He is board certified in genetic counseling by the American Board of Genetic Counseling. His research and policy work focus on health care provider education, rare disease test translation, oversight and regulation of genetic testing, quality control of genetic services, patient registries, and direct-to-consumer genetic testing. He is an active leader in the profession of genetic counseling. Mr. Faucett received his B.S. in biology from the Baptist College at Charleston and his M.S. in human genetics from Sarah Lawrence College.



Dianne M. Finkelstein, Ph.D., is a professor of medicine (biostatistics) at Harvard and the director of biostatistics at Massachusetts General Hospital. She has been on the faculty of Harvard School of Public Health and Harvard Medical School for 27 years. Dr. Finkelstein has made contributions to biostatistics methodology in survival analysis, carcinogenicity testing, clinical trials, and epidemiology. For the past 10 years, she has been the principal investigator of the Statistical Coordinating Center for the National Cancer Institute (NCI)-sponsored Cancer Genetics Network. This year she was awarded a Challenge Grant to initiate a Rare Cancer Genetics Registry. She received her Ph.D. in biostatistics from the University of Michigan.



Ian M. Fore, D.Phil., is the head of Biorepository and Pathology Informatics at the National Cancer Institute's Center for Biomedical Informatics and Information Technology. Previously Dr. Fore worked on drug discovery informatics at Wyeth Research and Johnson & Johnson Pharmaceutical Research and Development, including developing global databases for research data. More recently he was a product manager at Celera Genomics and was responsible for integrating Celera's informatics systems with those of its customers. He received his D.Phil. in physiology from the University of Oxford, England.



Lisa Forman, Ph.D., a staff scientist at the National Library of Medicine's National Center for Biotechnology Information (NCBI), focuses on the development of quality assessment software for high-throughput genotypes used in biomedical and forensic applications and the creation of bioinformatics resources to assist practitioners, patients, and the public. Her professional career includes nearly 20 years in forensic DNA testing, both as a practitioner/associate director at a private DNA company and as the chief of the Investigative and Forensic Sciences Division for the U.S. Department of Justice's National Institute of Justice. On sabbatical from the government, Lisa dedicated 2.5 years to a rare disease patient advocacy group where she initiated and implemented a traveling clinic supporting an NIH-sponsored research protocol while enhancing patient access to specialists with extensive experience in their disorders.



Christopher B. Forrest, M.D., Ph.D., is the Mary D. Ames Professor of Pediatrics at the Children's Hospital of Philadelphia (CHOP) and University of Pennsylvania School of Medicine. He holds an adjunct appointment in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. His academic focus is on pediatric population sciences, transforming children's health, and innovations in health care delivery. He has authored numerous scientific manuscripts and reviews, and his research is supported by a broad mix of funders, including the National Institutes of Health, the Centers for Disease Control and Prevention, the California Healthcare Foundation, the Commonwealth Fund, and the Robert Wood Johnson Foundation. He leads several large, multi-institutional research efforts that include development and application of child-reported health status measures, child health services research, and cross-national comparisons of health care. Dr. Forrest received his B.A. and M.D. from Boston University as part of a dual-degree program. He trained in pediatrics at CHOP, where he also served as chief resident, and he completed a Ph.D. in health services research at Johns Hopkins School of Public Health.



David S. Goldstein, M.D., Ph.D., conducts patient-oriented research on clinical neurocardiologic disorders, with an emphasis on catecholamine systems. At the National Institutes of Health (NIH), he obtained tenure at the National Heart, Lung, and Blood Institute (NHLBI), transferred to the National Institute of Neurological Disorders and Stroke (NINDS), and founded and leads the intramural Clinical Neurocardiology Section at NINDS. He is an authority on clinical catecholamine neurochemistry and disorders of the autonomic nervous system. His current research focuses on biomarkers and mechanisms of loss of catecholaminergic neurons in Parkinson disease and related disorders. He received a combined M.D./Ph.D. in behavioral science from Johns Hopkins University and house staff training at the University of Washington.



Leslie B. Gordon, M.D., Ph.D., is an associate professor of pediatrics research at Hasbro Childrens Hospital and the Warren Alpert Medical School of Brown University in Providence, Rhode Island, where she conducts her basic science research on Hutchinson-Gilford progeria syndrome (progeria), a rare, fatal genetic condition characterized by accelerated aging in children. She is a staff scientist at Children's Hospital Boston and Harvard University Medical School, where she conducts her clinical research on progeria. Dr. Gordon also is cofounder of The Progeria Research Foundation, Inc. (PRF) and serves as the organization's volunteer medical director.



Benjamin M. Greenberg, M.D., M.H.S., is the director of the Transverse Myelitis and Neuromyelitis Optica Program and the Pediatric Demyelinating Disease Program, deputy director of the Multiple Sclerosis Program, and assistant professor in the Department of Neurology at the University of Texas Southwestern. Dr. Greenberg is involved in a variety of research protocols and clinical trials. He received his M.P.H. in molecular microbiology and immunology from Johns Hopkins School of Public Health and his M.D. from Baylor College of Medicine. He completed a year of training in internal medicine at Rush-St. Luke's Presbyterian Hospital and performed his neurology residency at Johns Hopkins Hospital.



Stephen C. Groft, Pharm.D., is the director of the Office of Rare Diseases Research (ORDR) at the National Institutes of Health (NIH). His major focus is on stimulating research with rare diseases and developing information about rare diseases and conditions. To help identify research opportunities and establish research priorities, the ORDR has co-sponsored more than 1,000 rare diseases-related scientific conferences with the NIH research Institutes and Centers. Current activities include developing genetic tests for rare diseases, developing an educational module on rare diseases for school children, maintaining the Rare Diseases Clinical Research Network, establishing a public information center on genetic and rare diseases, and providing a special emphasis clinic with senior clinical staff for patients with undiagnosed diseases at NIH's Clinical Research

Center Hospital. He received his B.S. in pharmacy and his Pharm.D. from Duquesne University.



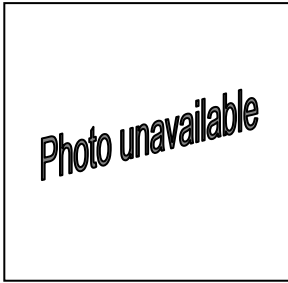
Paul A. Harris, Ph.D., is an associate professor of biomedical informatics and biomedical engineering at Vanderbilt University and serves as director of operations for the Vanderbilt CTSA Informatics Core and Office of Research Informatics. He has approximately 14 years of experience working in the field of clinical research informatics. His research interests include noninvasive measurement; storage and analysis of physiological data; research subject recruitment; and development of novel methods for collection, storage, and dissemination of research data. Dr. Harris is principal investigator for an 80-institution, 4,600 end-user collaboration project designed to provide research teams with flexible tools to plan and manage research data. He also has extensive experience in the design/support of volunteer participant registries. He received his Ph.D. in biomedical engineering from Vanderbilt University.



Sara Chandros Hull, Ph.D., currently directs the Bioethics Core of the National Human Genome Research Institute (NHGRI), which provides bioethics education, consultation, and administrative support to investigators in the intramural research program. She has been a member of the NHGRI Institutional Review Board for a decade and serves as its vice chair. Dr. Hull's research interests focus primarily on the intersection between research ethics and genetics. She also is interested in the complementary use of qualitative and quantitative research methods to understand a broad range of issues in bioethics in collaborative research with other members of the department. She received her undergraduate degree in molecular cell biology and genetics from Brandeis University and her Ph.D. from the Johns Hopkins Program in Law, Ethics, and Health.

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Julie Kaneshiro, M.A., is the policy team leader in the Office for Human Research Protections (OHRP), where she is involved in developing regulations and policies related to the Department of Health and Human Services (HHS) human subject protection regulations. Prior to joining OHRP, she worked at the National Institutes of Health (NIH) for more than 10 years, where she assisted in drafting the research provisions of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule.



Barbara I. Karp, M.D., served as the chief of the Neurology Consultation Service at the National Institute of Neurological Disorders and Stroke (NINDS) and as the chair of the NINDS Institutional Review Board (IRB). She established the Combined NeuroScience IRB, bringing together review of clinical research studies from six NIH intramural research programs related to neuroscience. She received her undergraduate and masters degrees from the Massachusetts Institute of Technology and her M.D. from Columbia University College of Physicians and Surgeons. She completed a residency in neurology at the George Washington University Medical Center and a fellowship in behavioral neurology at the National Institute of Mental Health.



George A. Komatsoulis, Ph.D., is the deputy director of the National Cancer Institute (NCI) Center for Bioinformatics and Information Technology (CBIIIT) and the acting chief information officer of the NCI. He draws upon more than two decades of experience in molecular biology and biomedical informatics to provide leadership on scientific and technical priorities and oversee the completion and implementation of technical and scientific standards across the group. Dr. Komatsoulis also leads the technical management of the caBIG program and has spearheaded deployment of caBIG to NCI Designated Cancer Centers and the National Community Cancer Centers Program (NCCCP). He received his Ph.D. in molecular biology and biochemistry from the California Institute of Technology and conducted postdoctoral work in the Department of Biochemistry at the Johns Hopkins University School of Medicine and the Department of Mathematics at the University of Southern California.



Susan M. Love, M.D., M.B.A., has dedicated her professional life to the eradication of breast cancer. As president of the Dr. Susan Love Research Foundation, she oversees an active research program centered on breast cancer prevention. She is a clinical professor of surgery at the University of California Los Angeles (UCLA) David Geffen School of Medicine; founder of Windy Hill Medical, a breast cancer drug device company; and founder and senior partner in LLuminari, a multimedia women's health company. Dr. Love's most recent project is a creative Internet solution to partnering women and scientists in accelerating basic translational research. The Love/Avon Army of Women is recruiting one million women who are willing to consider participating in research to find the cause and prevention of breast cancer. She received her M.D. from the State University of New York (SUNY) Downstate Medical Center in New York and her business degree from the Executive M.B.A. program at UCLA's Anderson School.

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Katherine R. McCurdy, M.B.A., is a founding member of the board of directors of the Barth Syndrome Foundation, Inc., and serves on that organization's scientific and medical advisory board. The group's mission is saving lives through education, advances in treatments, and finding a cure for Barth syndrome, an inborn error of metabolism with cardinal characteristics of cardiomyopathy, neutropenia, underdeveloped skeletal musculature, growth delay, and exercise intolerance. She also is a member of the review board of the Office of Rare Diseases Research (ORDR)-sponsored Collaboration, Education and Test Translation (CETT) Program, which encourages the translation of rare disease genetic tests from the research milieu to the clinical arena. As the mother of a son with Barth syndrome, she is strongly committed to facilitating scientific progress and improving treatments for those with rare disorders and to supporting the efforts of patient advocacy groups. She received her M.B.A. from the Harvard Business School and worked in various capacities in the corporate world before turning to the nonprofit sector.



Clement J. McDonald, M.D., is the director of the Lister Hill National Center for Biomedical Communications at the National Library of Medicine. He is a distinguished physician and scientist and one of the nation's most productive researchers in the field of electronic health records. He was the Regenstrief Professor of Medical Informatics and a distinguished professor of medicine at the Indiana University School of Medicine, where he developed the Regenstrief Medical Record system and published the first randomized trials showing the benefits of computer reminder systems and of physician order entry systems. He received his B.S. from the University of Notre Dame, his M.D. from the University of Illinois, and his M.S. from Northwestern University.

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Helen Moore, Ph.D., is the Biospecimen Research Network Program Manager in the Office of Biorepositories and Biospecimen Research (OBBR). Dr. Moore has a broad background in research and product development. She joined the NCI from Celera Genomics, where she led and managed cross-functional teams to develop bioinformatics products focused on comparative genomics and data visualization; developed new drug targets for complex diseases using multiple approaches including genetic analysis of disease association study data, biological pathways analysis, literature mining, and genomic analysis; and contributed to the assembly and annotation of the human genome. Dr. Moore's postdoctoral work focused on signal transduction in the wingless/Wnt-1 family of proto-oncogenes. She received her doctorate from Cornell University and her B.A. from Wellesley College. Her research experience includes work on human genomics and bioinformatics, fruit fly signaling, plant molecular biology, Alzheimer's disease, and synthetic skin.



Jonathan D. Moreno, Ph.D., is the David and Lyn Silfen University Professor of Ethics and a professor of medical ethics and history and sociology of science at the University of Pennsylvania. He holds a courtesy appointment as a professor of philosophy. He also is a senior fellow at the Center for American Progress in Washington, DC. Dr. Moreno has published more than 300 papers, reviews, and book chapters and is a member of several editorial boards. He received his B.A. in philosophy and psychology from Hofstra University and his Ph.D. in philosophy from Washington University.



Marsha A. Moses, Ph.D. is the Julia Dyckman Andrus Professor at Harvard Medical School and the director of the Vascular Biology Program at Children's Hospital Boston. The Moses laboratory has had a long-standing interest in identifying and characterizing the biochemical and molecular mechanisms underlying the regulation of angiogenesis during tumor progression, from the angiogenic switch through metastasis. To complement these studies, she established a proteomics-driven Biomarker Discovery Initiative in her laboratory that has now led to the discovery of noninvasive biomarkers that can predict disease status and stage in cancer patients and are also sensitive and specific markers of disease progression and therapeutic efficacy. A number of these urine tests are currently in clinical development. These biomarker studies have recently been expanded to include a number of rare diseases. Dr. Moses received her Ph.D. from Boston University and completed a National Institutes of Health postdoctoral fellowship at Children's Hospital Boston/Harvard Medical School and the Massachusetts Institute of Technology. Dr. Moses was elected to the Institute of Medicine of the National Academies of the United States in 2008.



Christopher A. Moskaluk, M.D., Ph.D., joined the faculty of the University of Virginia (UVA) School of Medicine in 1996 and is currently a tenured associate professor. He performs diagnostic surgical pathology as a clinical service at the UVA Medical System, is the director of the UVA Biorepository and Tissue Research facility, is the principal investigator of the Mid-Atlantic Division of the National Cancer Institute's (NCI) Cooperative Human Tissue Network, and heads an extramurally funded cancer research laboratory. For more than a decade he has been studying the molecular biology of adenoid cystic carcinoma, an uncommon human neoplasm that arises in the salivary glands and other glandular organs. He received his B.S. in microbiology from the University of Illinois in Champaign-Urbana and his M.D. and Ph.D. from Duke University, where his thesis work centered on the biochemistry of a viral transcriptional activator protein. He trained in anatomic pathology at the National Institutes of Health (NIH) Intramural Program and received fellowship training in gastrointestinal pathology and cancer genetics at the Johns Hopkins Medical Institutions.



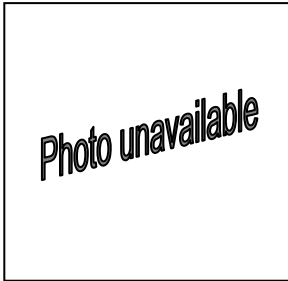
Stuart J. Nelson, M.D., is the head of the Medical Subject Headings Section of the National Library of Medicine. He has published extensively in the field of medical informatics, especially in the area of computerized vocabularies. His research interests are in the area of computer applications to medicine, and he collaborated for several years with Dr. Marsden S. Blois, one of the founders of the field of medical informatics. He received his bachelor's degree in mathematics from the University of California at Berkeley and his M.D. from the State University of New York.



Chalapathy Neti, Ph.D., B.S., is currently the associate director of health care transformation at IBM Research. Prior to this, he was an executive architect in the information agenda organization of the IBM Software Group, where he consulted with health care institutions to develop an information management strategy for improved outcomes and efficiency, and a senior manager for information analysis and interaction technologies at IBM Research, where he managed several research groups involved in developing text, image, and video analysis technologies and their application to biomedical informatics, medical imaging, and real-time decision intelligence. He has more than 20 years of advanced research and development experience. He received his Ph.D. in biomedical engineering from The Johns Hopkins University and his B.S from the Indian Institute of Technology, Kanpur.



P. Pearl O'Rourke, M.D., is the director of human research affairs at Partners HealthCare Systems in Boston and an associate professor of pediatrics at Harvard Medical School. She is responsible for the systems that support the regulatory and ethical oversight of human research and the responsible conduct of research. She also is chair of the Partners Healthcare System Embryonic Stem Cell Research Oversight (ESCRO) Committee. Dr. O'Rourke has worked as a pediatric critical care physician at the Children's Hospital, Boston, and at the Children's Hospital, University of Washington, Seattle, where she was the director of the Pediatric Intensive Care Unit. She performed a Robert Wood Johnson Health Policy fellowship working for Senator Edward Kennedy. Following this fellowship, she became the deputy director of the Office of Science Policy in the Office of the Director at the National Institutes of Health (NIH), where she worked on issues such as privacy, gene therapy (transfer), embryonic stem cells, and genetic discrimination.



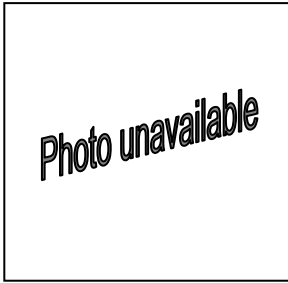
Wendy E. Patterson, J.D., is the senior advisor for extramural technology transfer at the Technology Transfer Center at the National Cancer Institute (NCI). Her responsibilities include serving as the NCI facilitator for the caBIG Data Sharing and Intellectual Capital (DSIC) Workspace; advising NCI extramural scientific program directors and their staff on data sharing and intellectual property matters arising from proposed grants, contracts, and cooperative agreements for collaborative research networks and consortia; drafting or reviewing related requests for grant applications and contract proposals; providing ongoing informal guidance and support to NCI extramural investigators and their institutions on management of intellectual property rights in accordance with NCI mission-related goals and NIH funding policies; reviewing contracts and subcontracts for the conduct of NCI's portion of cooperative group agreement efforts; developing agreements for the sharing of research materials and information through centralized consortia and repositories; and providing advice and support on intellectual property, technology transfer, and contractual matters to the NCI Center for Biomedical Informatics and Information Technology. Ms. Patterson received her A.B. in psychology and social relations from Harvard University and her J.D. from the University of Miami School of Law.



Vanessa Rangel Miller, M.S., C.G.C., is a certified genetic counselor and leads the DuchenneConnect Registry program. Based at Emory University in Atlanta, Georgia, she brings expertise in genetic testing and counseling from her experience as a laboratory genetic counselor and as a clinical counselor in prenatal and pediatric clinics. Vanessa is a member of the Congenital Muscular Dystrophy International Registry (CMDIR) Advisory Board and is actively involved with the TREAT-NMD Neuromuscular Network Registry Oversight Committee. She is a member of the 2010-2012 American College of Medical Genetics Program Committee. She received her M.S. from the University of North Carolina at Greensboro and her B.S. from the University of Washington. She is a member of the National Society of Genetic Counselors, World Muscle Society, and American College of Medical Genetics.



Rachel Richesson, M.S., Ph.D., M.P.H., is an associate professor of pediatrics at the University of South Florida (USF) College of Medicine. Dr. Richesson has helped to direct strategy for the identification and implementation of data standards for a variety of multinational multisite clinical research and epidemiological studies housed within the USF Department of Pediatrics, including the National Institutes of Health Rare Diseases Clinical Research Network (RDCRN). She co-chairs the RDCRN Standards and Registry Committees and interacts with standards bodies and other organizations to ensure that clinical research data representation needs are being addressed. She received her Ph.D. in health informatics from the University of Texas.



Daniel C. Russler, M.D., is vice president of clinical informatics for Oracle Health Sciences Strategy. His current role at Oracle includes creating strategies for health care standards, health care training, and new product development in health care intelligence and health care information exchange. Previously Dr. Russler held various administrative positions ranging from clinical to information systems, including associate administrator of hospital medical clinics and information systems, and focused on primary care, including private family medicine, hospice medicine, long-term care medicine, and acute care medicine. He earned his bachelor and medical degrees from the University of Wisconsin in Madison and trained in family practice at the University of Wisconsin Department of Family Medicine and Practice.



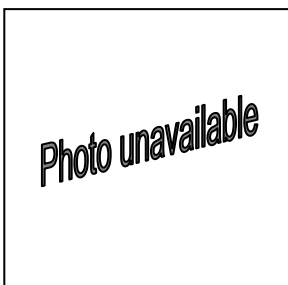
Jack Schwartz, J.D., is a visiting professor and health law and policy fellow at the University of Maryland School of Law. He previously served as a Maryland Assistant Attorney General for more than 25 years. He is currently a member of an institutional review board at the National Cancer Institute, a data and safety monitoring board for the National Institute on Aging, an advisory committee on health care-acquired infections for the Maryland Health Care Commission, ethics committees at the Johns Hopkins Hospital and Washington Hospital Center, and the advisory board of the Maryland Healthcare Ethics Committee Network. He also is a fellow of the American Bar Foundation. In recent years, he was a member of the State Advisory Council on Quality Care at the End of Life, the Maryland Stem Cell Research Commission, and the American Bar Association's Commission on Law and Aging. He served as a senior consultant to the National Bioethics Advisory Commission and a member of a national advisory committee for the Robert Wood Johnson Foundation. He received his B.A. from the University of Maryland Baltimore County and his J.D. from Yale Law School.



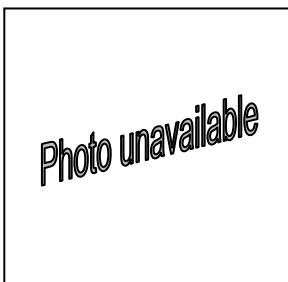
Joe V. Selby, M.D., M.P.H., is the director of the Division of Research (DOR), Kaiser Permanente Northern California's externally funded research shop. It is comprised of 45 M.D. and Ph.D. investigators who conduct a wide range of epidemiological and health services research and has an annual budget of more than \$80 million. Dr. Selby is a family physician, clinical epidemiologist, and health services researcher. His personal scientific interests and contributions include drug safety research, observational evaluations, and randomized quality improvement studies in diabetes mellitus and other chronic illnesses; studies of the efficacy of colon cancer screening; studies of variation in coronary angiography and revascularization following myocardial infarction; and the effects of cost-sharing in the emergency department and for prescription medications.



Robert H. Shelton, M.B.A., is the founder, chairman, and CEO of Private Access, Inc. Drawing upon his experiences heading a nonprofit disease advocacy group and in health care information systems, as an inventor, serial entrepreneur, and developer of complex public-private partnerships, he organized Private Access and coordinates the company's technology development efforts and strategy of building a patient-centric technology for simultaneously protecting patient privacy while speeding up the medical researchers' ability to find subjects for studies and clinical trials. Robert also serves as chairman of KS&A, a national nonprofit group serving several common genetics-based conditions. He received his undergraduate degree in public and international affairs from George Washington University and his M.B.A. from the University of Texas at Austin.



Jean R. Slutsky, P.A., M.S.P.H., is the director of the Center for Outcomes and Evidence (COE) at the Agency for Healthcare Research and Quality (AHRQ) of the U.S. Department of Health and Human Services. She oversees the Evidence-Based Practice Center Program; the Technology Assessment Program; the extramural and intramural research portfolios concerning translating research into practice and outcomes and effectiveness research, including pharmaceutical outcomes and cost-effectiveness analyses; and the National Guideline, Quality Measures, and QualityTools Clearinghouses. Ms. Slutsky received her B.S. from the University of Iowa, her M.S.P.H. in health policy and administration from the University of North Carolina at Chapel Hill, and her physician assistant training from the University of Southern California.



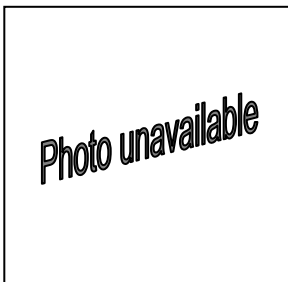
Simone S. Sommer, M.D., M.P.H., is president of the Chordoma Foundation, which she formed after her son Josh was diagnosed with a chordoma. The Chordoma Foundation is an innovative nonprofit organization uniting patients, doctors, and scientists to accelerate the development of effective treatments and, ultimately, a cure for this neglected form of bone cancer. Dr. Sommer is dedicated to improving the quality of life for people affected by chordomas and volunteers full time to achieve this mission. Under her direction, the Chordoma Foundation has raised \$1 million in 2.5 years and launched a coordinated international research effort that has invigorated the field of chordoma research and quickly led to breakthrough discoveries. Dr. Sommer is a graduate of George Washington University School of Medicine. She also holds an M.P.H. in epidemiology from the University of North Carolina School of Public Health.



Sharon F. Terry, M.A., is the president and CEO of the Genetic Alliance, a network transforming health by promoting an environment of openness centered on the health of individuals, families, and communities. She is the founding executive director of PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE). Following the diagnosis of their two children with PXE in 1994, Sharon and her husband founded and built a dynamic organization that fosters ethical research and policies and provides support and information to members and the public. She is at the forefront of consumer participation in genetics research, services, and policy and serves as a member of many of the major governmental advisory committees on medical research.



Jeffrey A. Thomas, B.S., the director of donor services for the National Disease Research Interchange (NDRI), is responsible for the management and expansion of NDRI's national tissue collection center network. This network includes 125 partnerships with organ procurement organizations (OPOs), tissue banks, eye banks, and medical centers. He has been in his role at NDRI for almost 5 years and has 20 years of experience in the procurement and preservation of organs and tissues for transplant. Prior to joining NDRI, Mr. Thomas was the director of tissue services and organ recovery and preservation at the Gift of Life Donor Program in Philadelphia, Pennsylvania. He received his B.S. from Neumann College and was certified as a medical technologist by the American Society of Clinical Pathologists, as an eye bank technician by the Eye Bank Association of America, and as a tissue bank specialist through the American Association of Tissue Banks.



Theresa Toigo, R.Ph., M.B.A., currently serves as the director of the Office of Special Health Issues at the Food and Drug Administration (FDA). The Office of Special Health Issues works with patients, their advocates, and health professional organizations to encourage and support their active participation in the formulation of FDA regulatory policy. Ms. Toigo joined the FDA in 1984. She has held a variety of positions in the Center for Drug Evaluation and Research, Center for Biologics Evaluation and Research, and the Office of the Commissioner. In addition to her current position, she also serves as the acting associate commissioner for external relations. Ms. Toigo has worked in hospital and retail pharmacy and continues to serve as a preceptor for pharmacy students. She received her B.S. in pharmacy and her M.B.A. from Rutgers University.



Santa J. Tumminia, Ph.D., is special assistant to the director of the National Eye Institute (NEI). She undertakes special assignments that involve program planning, science policy, intramural and extramural assignments, and special initiatives necessary to accomplish the mission of the NEI on behalf of the director. She has 20 years of experience in research and administration in government, nonprofit, and corporate environments. Dr. Tumminia has studied cataract formation and glaucoma and developed several methodological assays that are currently being used by researchers in the field. She has a B.S. in biology and received her M.S. and Ph.D. from Rensselaer Polytechnic Institute (RPI).



Jim B. Vaught, Ph.D., is the deputy director of the National Cancer Institute's (NCI) Office of Biorepositories and Biospecimen Research (OBBR). He has been working in the field of biorepository and biospecimen science for more than 15 years, the last 10 years at NCI. He was one of the founding members of the International Society for Biological and Environmental Repositories (ISBER) and its second president. He participated in the development of ISBER's Best Practices for Repositories, NCI's Best Practices for Biospecimen Resources, and the OBBR's other strategic initiatives. Since 2005 he has served as one of the NIH representatives to the Interagency Working Group on Scientific Collections, which was created by the Office of Science and Technology Policy. Dr. Vaught also is a member of the American Association for Cancer Research (AACR), the Association for Laboratory Automation, the American Society for Pharmacology and Experimental Therapeutics, and the American Association for Clinical Chemistry.



Michael S. Watson, Ph.D., F.A.C.M.G., is the director of the Health Resources and Services Administration's (HRSA's) National Coordinating Center for Regional Genetics and Newborn Screening Collaborative Groups and the National Institute of Child Health and Human Development (NICHD)/National Institutes of Health (NIH) Newborn Screening Translational Research Network (NBSTRN) Coordinating Center. He also is an adjunct professor of pediatrics at Washington University School of Medicine, executive director of the American College of Medical Genetics and the American College of Medical Genetics Foundation, and chair of the research work group of the Secretary's Advisory Committee on Heritable Disorders of Newborns and Children (ACHDNC). He received his Ph.D. in physiology and biophysics from the University of Alabama at Birmingham.